

## PLEASE COME, WALK WITH ME

***I am an eighty year old man .. with dementia .. and when I'm ready, I want MAiD.***

***We can walk this together - preferably hand-in-hand. With obstacles to clear, we can pace our way to fulfilling the promise of MEDICAL ASSISTANCE IN DYING(MAiD).***

***Let's start ..***

MAiD can be the most significant health legislation since the creation of Medicare in 1968. It began with the direction of the Supreme Court of Canada in February, 2015 (Carter Decision) for the Government of Canada to create laws to support, “**medically assisted choice of dying as a right for all Canadians.**” The previous law, “**forced patients to endure intolerable suffering against their wishes and denied them autonomy over their bodies.**”

The Court did not say the people with dementia, or people experiencing mental health problem, or minors (under 18 years) are lesser Canadians and need be excluded. The Court did not say that such persons are “vulnerable and need to be protected.” The original lawmakers added all of that in spite of any such recommendation from the Canadian Council of Academies(CCA) or the joint Senate/Parliamentarian Review Committee.

*(Within 18 months, three different lawsuits were filed in Provincial Courts - B.C., ON, and QC on behalf of suffering Canadians protesting the inadequacy of MAiD.)*

In February, the Federal Legislative Assembly introduced Bill C-7 in response to direction from the Superior Court of Quebec to correct an insufficiency of MAiD. C-7 dropped the ‘late-stage-requirement’ for Audrey Parker and would permit MAiD for people like the plaintiffs from Quebec (*Truchon & Gladu*). Good too, that people like Sue Rodriguez, Kay Carter and Julia Lamb whose “death could not be reasonably foreseeable” can finally be accommodated. Good for them, **but not people with dementia.** They are vulnerable and must be protected. It reduced the requirement of two independent witnesses to one .. and it also exchanged a ten-day “reflection period” for those facing imminent death for a ninety-day period for all others whose death may not be so imminent .. even though they may be experiencing extreme pain and agony. All in all, small steps in the right direction (as directed by the QC Superior Court) and a few “nudges” towards compliance with the original direction of the Supreme Court of Canada in 2015.

*(After creating C-7, the Federal Government requested and received a four-month dead line extension from the Superior Court of Quebec.)*

C-7 has since received two readings in the House of Commons and has been moved to the Senate. If it passes senate reading, it is expected to pass into law in the Legislative Assembly. C-7 is an improvement; unfortunately it is not enough. But there is more to come.

In January, the Government “consulted” the people of Canada. It provided access to a questionnaire type survey which closed in two weeks - January 27. It captured our attention with almost 300,000

respondents. More than any other survey, ever! Most surveys get less than 2200 respondents .. and at one point, the government had to shut it down. It lacked sufficient technical capacity to respond.

Do Canadians want a better MAiD? The answer is undoubtedly affirmative. A separate Leger Poll conducted during the same time period reported that almost 87% of all Canadians want a better MAiD.

Up to now, the Government has not provided a report nor a summary of the responses of their survey. Maybe it can't. Many respondents reported complete frustration with the questionnaire. *"It was far too ambiguous; it was too open-ended; what did it mean – all I wanted was to the right to ask for MAiD."*

Maybe we'll find out when it goes to the previously scheduled Review of MAiD in June.

***Are you still with me? We have miles to go, yet.***

What's with this June Review? With the original passage of MAiD in June 2016, the Federal Government contracted the Canadian Council of Academies (the same organization that created legislative suggestions to study and submit by December, 2018 a listing of possible problems with MAiD. Interestingly, the Government specified "problems" - not solutions nor suggestions. At the same time, the Government promised a Review of the Report and MAiD for June, 2020 - four years after C-14 became law.

The CCA Report is fascinating - particularly for academics. It's 224 pages is mostly conjecture and hypotheticals. It has some reality - problems reported in the Netherlands, Belgium, Switzerland and Oregon - all nations or a state which provide euthanasia.

*(By the way, these countries have had euthanasia laws for years - some more than twenty. Very few problems have been reported.)*

Isn't odd that our Government requested only problems? **Do we want problems or do we want solutions?**

Speaking of Belgium, here's what comes after almost twenty years of equivocation. They've just decided to change their laws to permit Advance Requests for anyone diagnosed with the prospect of facing an agonizing death. The patient can apply to his/her physician- in advance - while still cogent and not face any prospect of a protracted waiting (like a period of reflection). Dying assistance can be provided when it's wanted as specified in the request by either the patient or substitute decision maker. The request can be withdrawn at any time by the patient. Simple, easy and entirely based on private, doctor - patient considerations.

***Warning: we are now entering dangerous territory. I am going to kick aside some obstacles and go to a straight path Please stay with me.***

First of all, I want to dispense with all conjecture and hypotheticals. In the academic world, we can afford the time and the intellectual luxury of exploring possible problems in search of perfect solutions. But in the real world, we are more often limited to realities and what's possible. With our imperfect MAiD, we have real people in unendurable agony experiencing real despair in being denied a "beacon of hope." I have personally seen and heard real people pleading for help - many of whom resort to illegal drugs, voluntary starvation, or morphine from desperately harassed and sympathetic medical practitioners. *Our practitioners see, hear and feel the real agony and despair.* They know what to do and they can do it right away. But MAiD denies them any exercise of professional judgement and compassion.

Our bio-ethicists and academics are quick to jump in with warning .. "we must protect our vulnerable; we need safe-guards and procedures." Who are they really protecting .. the practitioner or the legislator? Not the patient who's pleading for help. His/her desperate cries go unheard while the 'doers' have to wade through all the protocols and bureaucratic procedures.

The patient is only vulnerable because s/he's not getting help - the help s/he has a right to receive. The 'doers' know reality: the academics only 'think' it. Real medical care is much more than an intellectual exercise.

MAiD is in danger of becoming a legalistic, bureaucratic procedure. It is not patient-centred. Why can't MAiD be considered as a medical practice and a consequence of a patient - physician discussion and decision?

Physicians deal with life/death decisions, choices and treatments all the time. We have used a "Do Not Resuscitate" medical procedure for years. The forms are in place and the practice is well established. We don't need a bio-ethical and academic review of the safe-guards and protocols. Additionally, a patient or substitute decision-maker can request palliative care sedation without enduring the rigours of forms and bureaucratic procedures. Why not MAiD - is it not medical care?

Abortion is legal and has been practised across this country for years. Not everyone agrees and possibly prospective mothers are vulnerable, but it is a personal choice of the patient and a consequence of a patient/physician decision. Why is MAiD regarded as something more different and difficult?

We have had safe-guards for medical practice for years. Colleges for physicians, nurses and all aspects of medical practice exist and are used by the 'doers' - the professionals to establish best practices and disciplines. They don't need outside laws (possibly 'bad' law), created by non-practitioners to manage and govern medical care.

How do you want to die? A straight-forward question .. and if you're older than fifty, you've likely thought about it. Most people answer with something like, "I don't know; maybe I'll just go to bed and not wake up." That's simple - no fuss, but most of all it's personal and private. It's also dignified .. and dignity is likely the most defining characteristic.

Most dying patients (and people in general) would say they don't want tubes, wires, beeping machines, soiled clothing .. and people they love, compelled to stand and watch - fearful, helpless and stricken with grief. And what does MAiD bring to the picture? Currently, it's two strangers or .. as defined by the legislation - two independent witnesses to observe and attest to a signature. C-7 reduces that requirement to one witness, but that's a meek concession to the need for dignity and privacy. During the past two years, my wife and I have volunteered to serve as independent witnesses through a service of Dying With Dignity - a national organization of people trying to support people seeking a better death. In more than sixty cases, we've been accepted by patients and family members with mixed feelings of resentment and relief. They don't want strangers, but they need us. They want privacy and they want dignity. The process of MAiD denies both. In fact, I worry that this so-called safeguard of requiring an independent witness stops many people in need from asking for such assistance simply because they don't want anyone to know - no one on the street, no one on the concession road, and no one in the community. **MAiD and the requesting of MAiD must be respected as a personal choice. There is no need for anyone to know but the patient and his/her physician.** Medically assisted dying must be private and confidential - just like any other medical procedure. To deny privacy is to deny dignity - and that's personal and most important to people choosing medical assistance in dying.

***And here's the last step we need to take and it's not dangerous or difficult. It's just 'good.'***

The national Alzheimer's Society of Canada has a wonderful policy .. **"Nothing About Us - Without Us."** A wonderful idea, simple and even easier to implement. Why is an academic better to have on the Review Panel than a person with dementia (or some other disease or condition leading to an agonized death)? By all means, the ultimate 'users' should be on the review panel. Just because they have been diagnosed with a problem doesn't immediately render them incapable of cogent and coherent thought. Most people, when diagnosed with dementia, have five to ten years left for rational and responsible thinking. They have actual (real) experience to share. They are available and willing - even anxious - to participate. Just ask them. Please!

***This is the end of our walk. Thanks for coming.***

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